

**ELECTRONIC GUIDE 1**

# Some key questions for inclusive involvement



## What is the purpose of this involvement?

If a clear purpose has not been identified, then ask yourself why you are doing it.

Check if agreement can be reached about what its purpose should be. If not, then reconsider going ahead with it.

## What change can happen as a result of this involvement?

If the answer to this question is 'we haven't thought about that' then:

- think very carefully about **why** you are holding this event.
- consider shifting the focus of the event so that there is a chance of positive change

## Have you the resources to carry it out in line with good practice?

Have you checked out good practice guides?

Are you able to meet the standards they suggest?

If not what can you do to get as close to them as possible?

If you still can't answer the question positively, then:

- Get expert guidance. Many service user controlled organisations are very experienced and skilled in accurately costing a user involvement activities.
- It is always advisable to have less service users involved than skimping on access requirements.
- Positively make the case for a larger budget or reconsider your plans.

## Have you allowed enough time?

Time is a key access issue. If the answer to this question is 'We don't know', then:

Get expert guidance from experienced service users and their organisations.

Time is essential for many reasons, to:

- identify who you want to involve
- find suitable, accessible venues or meeting places.
- find and book support workers like palantypists, British Sign Language (BSL) and other interpreters
- find out what additional access requirements participants might have, which could include helping with travel arrangements and accessible overnight accommodation
- by-pass any 'gate keepers'. Gate keepers are people who, for a variety of different reasons, consciously or unconsciously, make it difficult to get in touch directly with service users. They emerged in our project as a real barrier to involvement for a range of different service users. They may be for example, care staff, managers, or family members and they can help or stop people doing things.
- negotiate with 'community leaders', professionals' or 'representatives' to reach specific groups of service users. Involving community leaders or representatives is not the same as involving these specific service users, so don't stop with them.

Time for service users taking part in user involvement activities, for them to:

- put the date in their diaries (they do have other things to do!)
- put in place any travel arrangements, including assisted travel and a personal assistant for the day.
- organise any support arrangements, for example, child or respite care.
- if necessary, (for example, some people with learning difficulties), to arrange a pre meeting with a support worker so they can participate fully and on equal terms

...and so on and so on. That's why having enough time is crucial.

## Are you paying service users?

Many service users and their organisations now expect to be paid for sharing their expert 'knowledge by experience'. It is recognised good practice to offer payment. However this is not always straightforward, particularly if service users are receiving state welfare benefits. The issue of payment for service users receiving such benefits is a difficult

and complex one. It varies according to what benefits are involved and guidelines can be interpreted in different ways by different benefit offices. In some cases even if someone does not accept payment, there can still be implications for them in terms of benefits. Considerable expertise has now been developed on this issue, particularly by the Social Care Institute for Excellence and National Institute for Health Research Involve. Valuable first steps are to:

- Check with these organisations
- Check with local user led organisations
- Contact our local benefits agency office for their advice

## Who do you want to involve and why?

If you want to reach a specific group of service users, first ask yourself why? Are you sure you are not making assumptions about them or other groups. Is it really only them who should be involved? Once you are clear why you wish to engage with this group, there are further questions to ask:

- **Has anyone carried out similar work and can you learn from that?**  
Service users do not want to be asked the same questions repeatedly because people haven't bothered to check out what they have already said.
- **Does your organisation have existing links with this chosen group?**  
If so, wouldn't it be better to build on these links, rather than just asking more questions. If not, think carefully about how you are might be able to develop such links for the future from this exercise.

## How will you keep a record of what people say?

This needs careful consideration and requires resources. Any involvement activity which does not have an accurate record is unlikely to count for much. What is needed is the best possible compromise between accuracy, accessibility and a non-intrusive method of recording. Common methods used include:

- Minute/note taking
- Tape recording
- DVD/video recording

Each has strengths and weaknesses. Questions to ask are:

- Do we need a verbatim/full account of the meeting?
- Do we want to be able to access direct comments from participants?
- How will we be ensuring that participants can give their informed consent and how will we deal with a situation where some people may not want to be recorded?
- How can we ensure that all comments are recorded, given that participants may communicate in different ways?

There are other ways in which people's views can be logged, for example:

- Graffiti wall/post-it notes/flip charts encouraging people to say what they think
- Short recorded feedback sessions
- Video box opportunities to say what you think

All of these can be included as part of a report of the involvement activity.

## How will you deal with sensitive issues which may upset people?

Even when user involvement is focused on official and business matters, personal issues often come to the forefront. Service users, especially when this is a new experience for them frequently want to talk about their own personal and private experiences. This can leave them vulnerable and feeling exposed, especially if the exercise involves people concerned with the services they rely on. Issues of abuse may even come to light. This raises some key issues:

- How will you ensure confidentiality and anonymity from such involvement
- How will you keep a record of what people say and will they be safe?
- If problems emerge or people need support, what arrangements are there to ensure it is available?

## How will you feedback to participants?

This is absolutely crucial. Throughout the project we heard again and again that the major reason why service users became disillusioned with involvement initiatives was because nothing seemed to happen as a result and they got no feedback. It is fundamental therefore, to keep service users posted about what is happening in helpful and accessible ways. For example:

- What plans are there for feeding back to participants?
- How will you ensure that feedback is accessible and can reach as many people who got involved as possible?

## What are you doing to overcome particular barriers to involvement some people may face?

It is essential to think this issue through thoroughly. Check out this guide. Discuss possible barriers and ways of overcoming them with any people from groups that face such exclusions.

- Work out and set down what you plan to do to overcome such problems
- If at all possible discuss them with user led organisations with experience in involving such groups.
- Try and check out with members of such groups what they think about your plans.

## What action do you plan to take with what you find out?

The whole point of user involvement for most service users is bringing about positive change. It is not always possible to achieve such change, but nonetheless it is important to be clear about what is aimed for.

Some key questions to address include:

- What specific changes are possible as a result of planned user involvement?
- How realistic are these plans?
- If they are not achievable on this occasion, will there be further opportunities to try and do something about them?